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ABSTRACT

The presentation examines the challenge of advocacy for developmentally disabled people and their family members, and stresses the importance of a grass-roots basis for advocacy; it also describes the author's experiences as executive director of the Young Adult Institute, which operates community-based programs for mentally retarded and developmentally disabled clients. It is suggested that administrators' job responsibilities should include advocacy for a continuum of services and flexible, meaningful programs, and it is noted that advocacy involves changing attitudes as well as providing for services. The need for greater advocacy in four areas is described (sample recommended techniques in parentheses): (1) transforming public opinions and attitudes (using the mass media effectively); (2) facilitating dignified employment opportunities; (3) providing the fruits of technology (making technologies available); and (4) strengthening family support services (pressing for increased federal spending for such home-based services as crisis intervention, family counseling, respite services, and life planning). The paper concludes by noting the importance of advocating for the establishment of programs that offer freedom of choice and for programs and services which are flexible and which offer clients and parents a variety of options. (CL)

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ADVOCACY: A MOVING FORCE FOR QUALITY CARE

BY

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YOUNG ADULT INSTITUTE & WORKSHOP, INC.

PRESENTED AT:

THE AMERICAN ASSOCIATION ON MENTAL DEFICIENCY NATIONAL CONVENTION

PHILADELPHIA, PENNSYLVANIA

MAY 27-31, 1985

MY NAME IS JOEL LEVY, AND I AM HERE TO TALK TO YOU ABOUT ONE OF THE MOST IMPORTANT AND CRITICAL CHALLENGES FACING OUR PROFESSION IN THE 1980'S.

THE WAY IN WHICH WE RESPOND TO THIS CHALLENGE WILL HAVE A MAJOR IMPACT ON THE LIVES OF THOUSANDS UPON THOUSANDS OF DEVELOPMENTALLY DISABLED PEOPLE AND THEIR FAMILY MEMBERS. INDEED, I FIRMLY BELIEVE THAT THE WAY IN WHICH WE RESPOND TO THIS CHALLENGE--OUR EFFECTIVENESS--WILL DETERMINE THE VERY FUTURE OF OUR PROFESSION.

THE ISSUE WHICH I AM ABOUT TO DISCUSS IS ADVOCACY: THE ROLE WHICH ALL OF US--CLIENTS, PARENTS AND PROFESSIONALS--MUST ASSUME IN OUR STRUGGLE TO WIN HUMAN RIGHTS, FREEDOM, INDEPENDENCE AND DIGNITY FOR PEOPLE WITH DISABILITIES AND THEIR FAMILIES.

IF THERE IS ONE MESSAGE WHICH I WOULD LIKE TO IMPART TO YOU TODAY, IT IS THIS: ADVOCACY MUST BEGIN WITH EACH AND EVERY ONE OF US. IT MUST BE A GRASS-ROOTS EFFORT. IT MUST BECOME A PRIMARY AND PERMANENT ITEM ON OUR PERSONAL AGENDA, ON OUR PROFESSIONAL AGENDA, AS WELL AS ON THE AGENDA OF OUR AGENCY OR ORGANIZATION. WE MUST ENCOURAGE PARENTS AS WELL AS CLIENTS TO ADVOCATE FOR THEIR RIGHTS, AND WE MUST TRAIN THEM TO DO SO EFFECTIVELY.

LET ME MAKE IT CLEAR AT THE OUTSET THAT I AM NOT SPEAKING AS AN IMPARTIAL OBSERVER. I AM NOT NEUTRAL IN THIS STRUGGLE, AND I DON'T THINK THAT ANY OF US SHOULD OR CAN AFFORD TO BE.

MY COMMENTS TODAY ARE BASED ON MY EXPERIENCE AND PERSPECTIVE AS THE EXECUTIVE DIRECTOR OF ONE OF NEW YORK STATE'S LARGEST PROVIDERS OF COMMUNITY-BASED RESIDENTIAL AND CLINICAL SERVICES FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES, AS WELL AS ON MY ACTIVE INVOLVEMENT WITH NUMEROUS PROFESSIONAL AGENCIES AND ORGANIZATIONS WHICH ADVOCATE FOR THE RIGHTS OF PEOPLE WITH DISABILITIES.

OUR AGENCY, THE YOUNG ADULT INSTITUTE, PRESENTLY OPERATES 35 COMMUNITY-BASED PROGRAMS WHICH SERVE MORE THAN 1,000 MENTALLY RETARDED AND DEVELOPMENTALLY DISABLED CLIENTS AND THEIR FAMILY MEMBERS EVERY DAY OF THE YEAR, 24 HOURS A DAY. THE UNDERLYING PHILOSOPHY WHICH IS AT THE CORE OF OUR PROGRAMS IS THAT ALL OF OUR CLIENTS, REGARDLESS OF THEIR DISABILITY, HAVE THE POTENTIAL FOR GROWTH. ALL OF OUR PROGRAMS AND SETTINGS ARE DESIGNED TO MAXIMIZE THE CLIENTS' INVOLVEMENT IN DECISION-MAKING, REGARDLESS OF THEIR LEVEL OF DISABILITY.

I AM ALSO SPEAKING AS AN INDIVIDUAL WHO IS DEEPLY AND UNEQUIVOCALLY COMMITTED TO THE PRINCIPLE THAT MENTALLY RETARDED AND DEVELOPMENTALLY DISABLED PEOPLE ARE <u>ENTITLED</u> TO THE SAME RIGHTS AS ALL OTHER CITIZENS.

AS PROFESSIONALS IN THE FIELD OF DEVELOPMENTAL DISABILITIES, WE OBVIOUSLY HAVE A PROFESSIONAL AS WELL AS A MORAL OBLIGATION TO PROVIDE THE PEOPLE FOR WHOM WE CARE WITH THE BEST PROGRAMS AND SERVICES WHICH ARE AVAILABLE, AND TO ADVOCATE FOR A MORE ENLIGHTENED SOCIAL POLICY WHICH WILL ALLOW US TO ACHIEVE THIS.

IT IS ONLY NATURAL THAT THOSE OF US WHO ARE ADMINISTRATORS MUST CONCERN OURSELVES WITH THE DEVELOPMENT OF NEW PROGRAMS, WHILE THOSE OF US WHO ARE DIRECT SERVICE PROVIDERS MUST CONCERN OURSELVES WITH THE IMPLEMENTATION OF THESE SERVICES.

I WOULD LIKE TO SUGGEST TO YOU, HOWEVER, THAT THE DEVELOPMENT AND IMPLEMENTATION OF PROGRAMS ARE ONLY PART OF OUR JOB.

IF WE LIMIT OURSELVES TO THESE TASKS--REGARDLESS OF HOW WELL WE PERFORM THEM--WE SHALL BE DOING OUR CLIENTS A SERIOUS DISSERVICE. INDEED, I WOULD LIKE TO SAY TO YOU AS STRONGLY AS I CAN THAT ANY AGENCY OR PROFESSIONAL ASSOCIATION WHICH ABANDONS ITS ADVOCACY ROLE DOES SO AT ITS OWN PERIL AND COMMITS AN INJUSTICE AGAINST MENTALLY RETARDED AND DEVELOPMENTALLY DISABLED PEOPLE.

ONE OF OUR MAJOR RESPONSIBILITIES, THEREFORE, MUST BE--AND THIS IS BECOMING MORE RATHER THAN LESS IMPORTANT--ADVOCACY: ADVOCACY FOR TRANSITIONAL PROGRAMS, ADVOCACY FOR DIGNIFIED EMPLOYMENT OPPORTUNITIES, ADVOCACY FOR THE RIGHT TO LIVE IN THE LEAST RESTRICTIVE ENVIRONMENT, ADVOCACY FOR A CONTINUUM OF SERVICES, ADVOCACY FOR THE ESTABLISHMENT OF FLEXIBLE PROGRAMS WHICH PROVIDE MEANINGFUL OPTIONS AND CHOICES, AND ADVOCACY FOR FAMILY SUPPORT SERVICES WHICH WILL HELP KEEP FAMILIES TOGETHER.

THOSE OF US WHO HAVE FOUGHT SO LONG AND SO HARD FOR THE ESTABLISHMENT OF COMMUNITY-BASED PROGRAMS CAN DERIVE MUCH SATISFACTION FROM THE PROGRESS WHICH WE HAVE MADE.

WE CAN BE PROUD OF THE FACT THAT THOSE CHILDREN WHO ARE ENTERING THE EDUCATIONAL SYSTEM TODAY AND WHO WILL BECOME THE GRADUATES OF THE CLASS OF 2001 WILL NOT GRADUATE INTO INSTITUTIONS. INSTEAD, THEY MAY GRADUATE INTO COMMUNITY-BASED PROGRAMS WHERE THEY WILL BE PROVIDED WITH THE OPPORTUNITY TO GROW, TO ACHIEVE, AND TO LEAD MEANINGFUL, PRODUCTIVE AND DIGNIFIED LIVES.

BUT FOR THIS TO HAPPEN, WE WILL HAVE TO CONTINUE TO ADVOCATE AND FIGHT FOR THE ESTABLISHMENT OF A CONTINUUM OF QUALITY SERVICES FROM CHILDHOOD TO ADULTHOOD.

AS PROUD AS WE SHOULD BE OF OUR ACHIEVEMENTS, WE MUST NOT LOSE SIGHT OF THE FACT THAT OUR WORK HAS JUST BEGUN, AND THAT THE PEOPLE FOR WHOM WE CARE WILL CONTINUE TO COUNT ON OUR LEADERSHIP, OUR ADVOCACY, AND OUR SUPPORT IN HELPING THEM ATTAIN APPROPRIATE AND DIGNIFIED TRAINING, EMPLOYMENT AND HOUSING. WE MUST NOT LET THEM DOWN!

I WOULD LIKE TO STRESS THAT ADVOCACY INVOLVES CHANGING ATTITUDES AS WELL AS PROVIDING FOR SERVICES. ADVOCACY REFERS TO CHANGING OUR OWN ATTITUDES AS WELL AS THOSE OF OTHERS. IT MEANS CREATING STRUCTURES IN SOCIETY, AS WELL AS WITHIN OUR OWN AGENCIES, WHICH ENCOURAGE AND FACILITATE THE DEVELOPMENT AND DELIVERY OF HUMANE AND DIGNIFIED SERVICES. HOW <u>WE</u> TREAT OUR CLIENTS, THE EXTENT TO WHICH <u>WE</u> RESPECT AND VALUE THEM AS INDIVIDUALS, AND <u>OUR</u> EXPECTATIONS OF THEM WILL PLAY A MAJOR ROLE IN DETERMINING SOCIETY'S ATTITUDES TOWARDS THE PEOPLE WE SERVE. ALL OF US, THEREFORE, MUST SET THE TONE--SET AN EXAMPLE--IF PEOPLE WITH DISABILITIES ARE TO BE TREATED WITH DIGNITY AND RESPECT BY THE REST OF SOCIETY.

LET ME TAKE A FEW MINUTES TO OUTLINE TO YOU SOME OF THE AREAS IN WHICH THERE IS A NEED FOR GREATER ADVOCACY, AND TO DISCUSS SOME OF THE TOOLS AND RESOURCES WHICH ARE AVAILABLE TO US.

TRANSFORMING PUBLIC OPINION AND ATTITUDES

ONE OF OUR MOST IMPORTANT TASKS IS TO EDUCATE THE PUBLIC ABOUT THE NEEDS AND RIGHTS OF PEOPLE WITH DISABILITIES.

ALTHOUGH THE VARIOUS EXPOSES OF THE INHUMANE CONDITIONS AT WILLOWBROOK AND OTHER INSTITUTIONS SHOCKED AND STARTLED THE AMERICAN PUBLIC, I REGRET TO SAY THAT EVEN THE MOST VOCAL CRITICS OF INSTITUTIONS GREET THE PROSPECT OF A COMMUNITY RESIDENCE BEING ESTABLISHED IN THEIR DOMAIN WITH THE FAMILIAR CRY OF "NOT IN MY NEIGHBORHOOD."

I DON'T KNOW HOW MANY OF YOU SAW THE STORY IN THE NEW YORK TIMES LAST MONTH. THE RESIDENTS OF A CERTAIN AREA IN CONNECTICUT CLAIMED THAT THE PROPERTY VALUE OF THEIR HOMES COULD GO DOWN BECAUSE A FACILITY FOR PEOPLE WITH MENTAL DISABILITIES WAS ESTABLISHED IN THEIR NEIGHBORHOOD.

BELIEVE IT OR NOT, AN AMERICAN COURT AGREED WITH THESE HOMEOWNERS AND ORDERED THAT THEIR PROPERTY TAXES BE REDUCED. AS SHAMEFUL AS IT MAY SOUND, AND DESPITE NUMEROUS STUDIES WHICH HAVE SHOWN THAT HOMES FOR THE DISABLED OFTEN IMPROVE THE QUALITY OF A NEIGHBORHOOD, AN AMERICAN COURT RULED IN EFFECT THAT PEOPLE WITH DISABILITIES ARE SECOND CLASS CITIZENS.

THIRTY YEARS AGO SOME PEOPLE MADE THE ARGUMENT THAT THEIR PROPERTY VALUES WOULD COME DOWN IF A JEW MOVED INTO THEIR NEIGHBORHOOD. THEY ARE NOT MAKING THIS ARGUMENT TODAY AND, IF THEY DID, THEY WOULDN'T GET AWAY WITH IT.

TWENTY YEARS AGO, AND EVEN 10 YEARS AGO, SOME PEOPLE MADE THE SAME ARGUMENT IN ORDER TO KEEP BLACKS FROM MOVING INTO THEIR NEIGHBORHOODS. BUT THEY CAN'T MAKE THIS ARGUMENT NOW AND GET AWAY WITH IT.

BUT TODAY, IN 1985, SOME PEOPLE ARE SAYING THAT MENTALLY DISABLED PEOPLE SHOULD BE KEPT OUT OF THEIR NEIGHBORHOOD BECAUSE THEY MAY BRING DOWN PROPERTY VALUES. AND TODAY, IN 1985, THEY ARE <u>STILL</u> GETTING AWAY WITH IT!

SO, YOU SEE, OUR STRUGGLE TO CHANGE THE PUBLIC'S ATTITUDE HAS ONLY JUST BEGUN. INDEED, AS THE PROCESS OF DEINSTITUTIONALIZATION PROCEEDS AND MORE AND MORE PEOPLE ARE RETURNED TO THEIR COMMUNITIES, WE MUST CONTINUE TO EDUCATE THE PUBLIC NOT ONLY ABOUT THE <u>NEEDS</u> OF MENTALLY RETARDED AND DEVELOPMENTALLY DISABLED PEOPLE, BUT ABOUT THEIR <u>RIGHTS</u> AND CAPABILITIES AS WELL.

ONE OF THE THINGS WHICH WE MUST DO IS TO LEARN HOW TO USE THE <u>MASS MEDIA</u> MORE EFFECTIVELY IN ORDER TO IMPROVE THE IMAGE OF AND BRING DIGNITY INTO THE LIVES OF PEOPLE WITH DISABILITIES.

AS WE ALL KNOW, TELEVISION PLAYS A SIGNIFICANT ROLE IN SHAPING OUR ATTITUDES AND PERCEPTIONS ABOUT EVERYTHING FROM SOAP TO POLITICIANS. TELEVISION HAS A GREAT POTENTIAL TO EDUCATE, AND WE OUGHT TO TAKE GREATER ADVANTAGE OF IT.

FOR EXAMPLE, SESAME STREET, WHICH INCLUDES A DOWN'S SYNDROME CHILD IN ITS CAST, HAS ALREADY DEMONSTRATED THAT DEVELOPMENTALLY DISABLED PEOPLE CAN BE PORTRAYED IN A POSITIVE AND FAVORABLE LIGHT.

THIS IS EXTREMELY SIGNIFICANT BECAUSE IT ACCOMPLISHES TWO THINGS AT THE SAME TIME: IT IMPROVES THE PUBLIC'S PERCEPTION REGARDING PEOPLE WITH DISABILITIES, AND IT ENHANCES THE SELF-IMAGE OF DEVELOPMENTALLY DISABLED INDIVIDUALS EVERYWHERE. THERE IS NO REASON WHY OTHER TELEVISION PROGRAMS COULD NOT FOLLOW SESAME STREET'S EXAMPLE OF PORTRAYING DISABLED PEOPLE AS INDIVIDUALS WHO HAVE ABILITIES, TALENTS, AND POTENTIAL.

MOREOVER, SINCE TELEVISION PROGRAMS AND NEWSPAPER COLUMNS PROVIDE INFORMATIONAL AND EDUCATIONAL SERVICES TO ALL SEGMENTS OF OUR POPULATION, THEY OUGHT TO PROVIDE SIMILAR SERVICES TO PEOPLE WITH DISABILITIES. THE MASS MEDIA IS A POWERFUL TOOL. BY CHANGING PERCEPTIONS AND ALTERING ATTITUDES, IT CAN PROVIDE THE PEOPLE WE SERVE WITH GREATER OPPORTUNITIES THAN EVER BEFORE.

BUT NONE OF THIS WILL HAPPEN UNLESS WE MAKE IT HAPPEN; UNLESS WE ADVOCATE FOR THE RIGHTS OF PEOPLE WITH DISABILITIES; AND UNLESS WE PROVIDE THE MEDIA WITH THE INFORMATION, UNDERSTANDING, AND SENSITIVITY WHICH THE MEDIA REQUIRES TO PROMOTE AND SUPPORT THE NEEDS OF THE PEOPLE WE SERVE.

I WOULD LIKE TO OUTLINE FOR YOU SOME OF THE STEPS WHICH WE HAVE TAKEN AT YAI--AND WHICH ALL OF YOU CAN TAKE--TO KEEP THE MEDIA INFORMED ABOUT AND SENSITIVE TO THE NEEDS OF THE PEOPLE WE SERVE.

A. <u>INVITE REPORTERS TO VISIT YOUR PROGRAMS.</u> FAMILIARIZE THEM WITH THE WORK YOU DO AND WITH THE PEOPLE YOU SERVE, AND YOU WILL TURN THEM INTO YOUR ALLIES. OPEN HOUSES AND ANNIVERSARY CELEBRATIONS ARE ESPECIALLY GOOD TIMES TO INVITE THE PRESS. BE SURE TO INVITE POLITICAL FIGURES AS WELL. REPORTERS LIKE TO COVER POLITICIANS, AND POLITICIANS LOVE TO BE COVERED BY THE MEDIA. OF COURSE, IN ORDER TO DO A STORY, REPORTERS NEED ISSUES. IF THERE IS ONE THING WHICH OUR PROFESSION HAS IT IS ISSUES: AGING OUT; SHORTAGE OF COMMUNITY BEDS; ETC. REPORTERS ARE ALSO INTERESTED IN TOUCHING, EMOTIONAL HUMAN INTEREST STORIES, AND GOD KNOWS THAT WE HAVE PLENTY OF THOSE.

B. MAKE YOURSELF AVAILABLE FOR PRINT, RADIO AND TELEVISION INTERVIEWS. LET THEM KNOW YOU ARE AROUND. WE AT YAI HAVE WORKED VERY HARD TO ESTABLISH EXCELLENT CONTACTS WITH THE MEDIA. REPORTERS KNOW THAT WHEN A STORY ABOUT DEVELOPMENTAL DISABILITIES BREAKS OUT, THEY CAN RELY ON US FOR FAST, RELIABLE AND AUTHORITATIVE INFORMATION. THANKS TO OUR TIES WITH THE MEDIA, WE HAVE BEEN ABLE TO TELL OUR STORY ON "20/20", ON THE LOCAL AFFILIATES OF ABC, CBS AND NBC, ON THE INDEPENDENT TELEVISION STATIONS, ON NUMEROUS RADIO PROGRAMS, IN THE NEW YORK TIMES, AS WELL AS IN MANY OTHER PUBLICATIONS.

C. MONITOR THE MEDIA AND RESPOND TO IT. WHEN A STORY PERTAINING TO PEOPLE WITH DISABILITIES APPEARS ON TELEVISION OR IN THE NEWSPAPER, LET THE EDITOR KNOW EXACTLY HOW YOU FEEL ABOUT THE STORY. IF THE STORY IS NEGATIVE, PREJUDICED OR MISINFORMED, PROVIDE THE EDITOR WITH THE FACTS. BE POLITE, BUT REMIND THE EDITOR THAT PEOPLE WHO ARE MENTALLY RETARDED ARE ENTITLED TO THE SAME RIGHTS AS ALL OTHER CITIZENS. IF A REPORTER WRITES A STORY WHICH DEMONSTRATES SPECIAL SENSITIVITY, LET THE REPORTER KNOW HOW MUCH YOU APPRECIATE HIS OR HER SENSITIVITY. AT YAI WE HAVE USED CERTAIN OCCASIONS--OUR PARENTS DINNER DANCE, OUR BOARD OF TRUSTEES EVENT--TO HONOR THOSE REPORTERS WHO HAVE CONTRIBUTED TO A GREATER PUBLIC UNDERSTANDING OF THE NEEDS AND RIGHTS OF PEOPLE WITH DISABILITIES. SOME OF THE MEDIA PEOPLE WE HAVE RECENTLY HONORED INCLUDE GERALDO RIVERA AND BARBARA WALTERS.

D. PREPARE AND DISTRIBUTE TO THE MEDIA PUBLIC SERVICE ANNOUNCEMENTS (PSA'S) REGARDING THE RIGHTS, CAPABILITIES AND SERVICES FOR PEOPLE WITH DISABILITIES. WE RECENTLY HAD ONE OF OUR CLIENTS FEATURED IN A PUBLIC SERVICE ANNOUNCEMENT WHICH WAS PRODUCED WITH THE HELP OF THE PRESIDENT'S COMMITTEE ON EMPLOYMENT OF THE HANDICAPPED, AND WHICH ADVOCATES FOR INCREASED OPPORTUNITIES IN INDUSTRY FOR PEOPLE WITH DISABILITIES.

DIGNIFIED EMPLOYMENT OPPORTUNITIES

LET ME SAY A FEW MORE WORDS ABOUT COMPETITIVE EMPLOYMENT. IT IS WELL KNOWN THAT PEOPLE DERIVE THEIR SENSE OF SELF-WORTH FROM THEIR JOBS. JOBS PROVIDE INDIVIDUALS WITH A SENSE OF SELF-FULFILLMENT AND DIGNITY.

DEVELOPMENTALLY DISABLED PEOPLE, LIKE EVERYONE ELSE, ARE ENTITLED TO THE OPPORTUNITY TO SUCCEED AS WELL AS TO FAIL. WHY NOT PROVIDE THOSE WHO ARE CAPABLE WITH THE OPPORTUNITY TO RECEIVE ON-THE-JOB TRAINING IN THE PRIVATE SECTOR? GOVERNMENT, WHICH HAS PROVIDED TAX INCENTIVES TO ENCOURAGE THE TRAINING AND HIRING OF VARIOUS GROUPS, OUGHT TO DO THE SAME IN A REALISTIC AND WORKABLE PROGRAM GEARED TO PEOPLE WHO ARE MENTALLY RETARDED AN DEVELOPMENTALLY DISABLED. COMPETITIVE EMPLOYMENT WOULD PROVIDE THE DEVELOPMENTALLY DISABLED INDIVIDUAL WITH A TRUE SENSE OF ACCOMPLISHMENT, AND WOULD DEMONSTRATE TO SOCIETY THAT PEOPLE WITH DISABILITIES ARE, IN FACT, PRODUCTIVE MEMBERS OF THE COMMUNITY.

I AM PROUD TO SAY THAT MY AGENCY, THE YOUNG ADULT INSTITUTE, HAS RECENTLY DEVELOPED A MODEL PROGRAM DESIGNED TO FACILITATE AND FOSTER THE EMPLOYMENT OF DEVELOPMENTALLY DISABLED YOUNG ADULTS WHO ARE IN TRANSITION FROM SCHOOL TO ADULT SETTINGS. I AM ALSO PROUD THAT SOME OF OUR OWN CLIENTS ARE PRESENTLY EMPLOYED BY MAJOR COMPANIES, WORKING SIDE BY SIDE WITH THEIR NON-DISABLED COLLEAGUES, AND THAT WE GET NOTHING BUT EXCELLENT REPORTS ABOUT THEM.

BUT, UNFORTUNATELY, THERE ARE THOUSANDS UPON THOUSANDS OF MENTALLY DISABLED INDIVIDUALS THROUGHOUT THE UNITED STATES WHOSE POTENTIAL IS BEING WASTED BECAUSE NO ONE WILL GIVE THEM A CHANCE.

LET ME SAY THAT THEY DESERVE A CHANCE. LIKE THE REST OF US, THEY SHOULD HAVE AN OPPORTUNITY TO PROVE THEMSELVES.

BUT THIS WILL NOT HAPPEN UNLESS WE MAKE IT HAPPEN. UNLESS WE ADVOCATE FOR IT. UNLESS WE MAKE THE GOVERNMENT, THE PRIVATE SECTOR AND THE PUBLIC AWARE OF THE POTENTIAL AND RIGHTS OF PEOPLE WITH DISABILITIES.

PROVIDING THE FRUITS OF TECHNOLOGY

LET ME MOVE ON TO ANOTHER AREA WHICH IS OF TREMENDOUS IMPORTANCE TO THE PEOPLE FOR WHOM WE CARE.

WE HAVE RECENTLY ENTERED A REVOLUTIONARY AND EXCITING COMPUTER AGE WHOSE POSSIBILITIES ARE LIMITED ONLY BY OUR OWN IMAGINATION. THERE IS NO REASON WHY THE NEW TECHNOLOGY CANNOT BE APPLIED TO SERVE THE NEEDS AND OVERCOME THE DISABILITIES OF PEOPLE WITH HANDICAPS. COMPUTER TECHNOLOGY COULD ONE DAY CONTRIBUTE TO THE INDEPENDENCE, SELF-SUFFICIENCY, AND DIGNITY OF DISABLED INDIVIDUALS BY PROVIDING MOBILITY TO THE NON-AMBULATOR SPEECH TO THE NON-VERBAL, SIGHT TO THE BLIND, AND HOPE TO THE DISHEARTENED. INDEED, THE NEW TECHNOLOGY MAY SOON BE CAPABLE OF DETECTING, DIAGNOSING, AND TREATING DEVELOPMENTAL DISABILITIES IN THE PRE-NATAL STATE. WE ARE TALKING ABOUT DEVELOPMENTS WHICH MAY PROVIDE UNPARALLELED OPPORTUNITIES AND BRING NEW HOPE TO THOUSANDS UPON THOUSANDS OF PEOPLE.

A FEW WEEKS AGO THE YOUNG ADULT INSTITUTE SPONSORED A NATIONAL CONFERENCE ON "MODEL PROGRAMS AND NEW TECHNOLOGIES FOR PEOPLE WITH DISABILITIES."

OUR SPEAKERS, WHO CAME FROM THROUGHOUT THE UNITED STATES, SPOKE ABOUT WONDERFUL AND EXCITING PRODUCTS WHICH CAN MAKE PEOPLE WITH DISABILITIES LESS DEPENDENT AND MORE INDEPENDENT; NEW TECHNOLOGIES WHICH CAN HELP THEM GAIN GREATER CONTROL OVER THEIR ENVIRONMENT; TECHNOLOGIES WHICH CAN PROVIDE THEM WITH THE OPPORTUNITIES TO DETERMINE THEIR OWN DESTINIES; TECHNOLOGIES WHICH CAN BRING THEM <u>FREEDOM!</u>

SOME OF THESE PRODUCTS AND TECHNOLOGIES ARE STILL IN THE PLANNING STAGE WHILE OTHERS ALREADY EXIST. BUT TO BECOME MEANINGFUL, THEY MUST BE MADE AVAILABLE TO PEOPLE WITH DISABILITIES. WE MUST ADVOCATE FOR THIS TO HAPPEN.

BUT, AGAIN, THIS WILL NOT HAPPEN UNLESS WE MAKE IT HAPPEN; UNLESS WE PLAN FOR IT; AND UNLESS WE ADVOCATE FOR THE PEOPLE WE SERVE.

I WOULD LIKE TO ADD IN THIS CONTEXT THAT WE USE ALL OF OUR CONFERENCES AS WELL AS OUR PROFESSIONAL PUBLICATIONS FOR THE PURPOSE OF ADVOCACY.

OUR LAST YEAR'S CONFERENCE, "CRITICAL ISSUES IN COMMUNITY CARE FOR THE UNDERSERVED" FOCUSSED ON AND ADVOCATED FOR THE NEED OF PEOPLE WHO ARE DUAL DIAGNOSED, AUTISTIC, MULTIPLY HANDICAPPED, ELDERLY, AS WELL AS ON THE NEEDS OF OTHER NEGLECTED AND UNDERSERVED POPULATIONS.

OUR NEXT YEAR'S CONFERENCE, WHICH WILL BE HELD IN APRIL OF 1986, WILL FOCUS ON THE NEEDS OF PARENTS. HOW TO PROVIDE FOR THOSE NEEDS WHICH WILL STRENGTHEN THE FAMILY UNIT.

WE HAVE ALSO FORMED THE YAI PRESS WHICH FACILITATES OUR ADVOCACY EFFORTS THROUGH THE PUBLICATION OF MONOGRAPHS AND BOOKS DEALING WITH A VARIETY OF CRITICAL ISSUES.

WE HAVE ESTABLISHED A NUMBER OF PROFESSIONAL AND ADVISORY COMMITTEES--A MEDICAL COMMITTEE, A SPORTS COMMITTEE AND OTHERS--WHICH HELP US ADVOCATE IN THEIR RESPECTIVE PROFESSIONS.

FINALLY, WE HAVE PREVAILED UPON A NUMBER OF MAJOR CORPORATIONS, INCLUDING MANUFACTURERS HANOVER TRUST, TO HOST CORPORATE LUNCHEONS AND RECEPTIONS. WE HAVE USED THESE OCCASIONS TO MAKE VIDEO PRESENTATIONS OF OUR WORK; TO ACQUAINT CORPORATE LEADERS WITH THE CHALLENGES WHICH CONFRONT OUR PROFESSION; AND TO URGE THESE LEADERS TO JOIN US IN FORMING A PARTNERSHIP FOR HUMAN DIGNITY WHICH WILL ADVOCATE AND WORK FOR EQUAL RIGHTS FOR THE PEOPLE FOR WHOM WE CARE.

FAMILY SUPPORT SERVICES

ANOTHER GREAT NEED FOR WHICH ALL OF US MUST ADVOCATE IS FAMILY SUPPORT SERVICES.

I DON'T NEED TO TELL ANY OF YOU THAT A FAMILY WHICH PROVIDES CONTINUOUS CARE FOR A CHILD OR AN ADULT WITH A DEVELOPMENTAL DISABILITY IS OFTEN CONFRONTED WITH ECONOMIC, SOCIAL AND PSYCHOLOGICAL STRESS WHICH MAY FORCE IT TO MAKE THE RELUCTANT AND DIFFICULT DECISION TO SEEK OUT-OF-HOME PLACEMENT FOR THE DISABLED FAMILY MEMBER.

I CAN TELL YOU THAT THERE COMES A TIME IN THE LIFE OF EVERY FAMILY WHICH CARES FOR A DEVELOPMENTALLY DISABLED FAMILY MEMBER AT HOME WHEN IT IS CONFRONTED WITH A CRISIS. IT IS USUALLY IN THE COURSE OF SUCH A CRISIS--i.e. SERIOUS ILLNESS, DEATH IN THE FAMILY, DIVORCE, EMPLOYMENT RELOCATION OR UNEMPLOYMENT--THAT THE FAMILY, SEEKING TEMPORARY RELIEF FROM ITS ENORMOUS RESPONSIBILITIES, IS MOST SUSCEPTIBLE TO SEEKING OUT-OF-HOME PLACEMENT AS THE SOLUTION TO THE PROBLEM.

WITHOUT A DOUBT, THE SUCCESS OR FAILURE OF KEEPING A DISABLED FAMILY MEMBER LIVING AT HOME DEPENDS TO A LARGE EXTENT ON THE FAMILY'S ABILITY TO COPE WITH THE DEMANDS PLACED UPON IT. THIS, IN TURN, DEPENDS UPON THE EXTENT AND NATURE OF THE SERVICES WHICH ARE MADE AVAILABLE TO SUCH FAMILIES.

IT MAY SURPRISE MANY OF YOU, BUT <u>OVER 80 PERCENT OF ALL PERSONS WITH A DEVELOPMENTAL DISABILITY LIVE AT HOME AND HAVE NEVER BEEN PLACED IN AN INSTITUTION OR IN A COMMUNITY RESIDENCE.</u>

YET, AS INCREDIBLE AS IT MAY SOUND, WE ARE TOLD THAT HOME-BASED SERVICES CURRENTLY RECEIVE LESS THAN ONE PERCENT OF THE TOTAL FEDERAL BUDGET EXPENDED FOR HEALTH AND SOCIAL SERVICES (LOOP & HITZING, P. 17). IN NEW YORK STATE, I AM SORRY TO SAY, A DISPROPORTIONATE PERCENTAGE OF THE BUDGET IS SPENT EACH YEAR TO SUPPORT THE PLACEMENT OF CHILDREN OUT OF THEIR NATURAL HOMES, WHEREAS ONLY A SMALL AMOUNT IS ALLOCATED TO ASSIST FAMILIES IN KEEPING THEIR DEVELOPMENTALLY DISABLED CHILDREN AT HOME WHERE, MORE OFTEN THAN NOT, THEY BELONG.

MOREOVER, THOSE SERVICES WHICH ARE BEING PROVIDED ARE DELIVERED IN A SCATTERED, ISOLATED FASHION WHICH REDUCES THEIR EFFECTIVENESS AND DIMINISHES THE BENEFITS WHICH THEY ARE INTENDED TO PROVIDE. THERE EXISTS NO CONTINUUM OF SERVICES.

WHAT THESE FACTS AND FIGURES TELL US, THEREFORE, IS THAT THERE EXISTS A DESPERATE NEED FOR FAMILY SUPPORT SERVICES.

THESE SERVICES MUST INCLUDE:

A. CRISIS INTERVENTION/STABILIZING SERVICES.

B. FAMILY COUNSELING SERVICES.

C. IN-HOME TRAINING SERVICES.

D. RESPITE SERVICES, AND

E. LIFE PLANNING SERVICES.

THE PROVISION OF THESE SERVICES WOULD BE FACILITATED BY:

1. THE ADOPTION OF A HOLISTIC APPROACH WHICH WOULD RECOGNIZE THAT CARING FOR A MENTALLY DISABLED FAMILY MEMBER AT HOME IS A CONCERN WHICH INVOLVES THE ENTIRE FAMILY. HOME CARE SERVICES, THEREFORE, SHOULD ADDRESS THE NEEDS OF THE ENTIRE FAMILY.

2. THE DEVELOPMENT OF A COMPREHENSIVE AND INTEGRATED DELIVERY SYSTEM WHICH WOULD PROVIDE SERVICES IN A COORDINATED FASHION SO AS TO ENHANCE THEIR EFFECTIVENESS AND IMPACT.

3. THE ELIMINATION OF ALL FISCAL DISINCENTIVES FOR PARENTS WHO CARE FOR THEIR CHILDREN WITH SEVERE DISABILITIES AT HOME.

4. THE ATTAINMENT OF A WAIVER OF MEDICAID ELIGIBILITY REQUIREMENTS FOR INDIVIDUALS WHO WOULD QUALIFY FOR SSI FUNDING IF NOT FOR THE THEIR FAMILY'S INCOME LEVEL.

5. THE ESTABLISHMENT OF A COMPREHENSIVE PLAN WHICH WOULD PERMIT PRIVATE AGENCIES TO PROVIDE FAMILY SUPPORT SERVICES IN A WELL-PLANNED, COORDINATED FASHION. THE STATES CAN ENCOURAGE THIS BY SETTING UP A HOME CARE SYSTEM WHICH IS GEARED SPECIFICALLY TO MEETING THE NEEDS OF DEVELOPMENTALLY DISABLED PEOPLE AND THEIR FAMILIES.

I WOULD LIKE TO MAKE IT VERY CLEAR THAT NONE OF THESE SERVICES IN INTENDED TO REPLACE OR USURP THE ROLE OF THE FAMILY. ON THE CONTRARY, THEY ARE DESIGNED TO STRENGTHEN THE FAMILY, INDEED, TO KEEP FAMILIES TOGETHER.

I AM PROUD TO SAY, BY THE WAY, THAT MY AGENCY, THE YOUNG ADULT INSTITUTE, HAS MADE A STRONG COMMITMENT TO THE PROVISION OF FAMILY SUPPORT SERVICES.

WE HAVE RECENTLY DEVELOPED A DEMONSTRATION RESPITE PROGRAM WHICH OFFERS A WIDE VARIETY OF RESPITE OPTIONS. PARENTS MUST BE PROVIDED WITH CHOICES SO THAT THEY ARE ABLE TO SELECT AN OPTION WHICH MEETS THEIR NEEDS.

ON A MUCH BROADER SCALE, THE YOUNG ADULT INSTITUTE HAS JUST DEVELOPED AND IS NOW PRODUCING A NEW TELEVISION SERIES ENTITLED "TIPS" (TELEVISION INSTRUCTION FOR PARENT SUPPORT) WHICH WILL PROVIDE FAMILIES OF MENTALLY RETARDED PEOPLE WITH VARIOUS SUPPORT SERVICES SUCH AS COUNSELING, TRAINING, CRISIS INTERVENTION, AND INFORMATION IN THE MOST ACCESSIBLE PLACE--IN THE HOME.

FOR THOSE OF YOU WHO ARE INTERESTED IN THESE AND THE OTHER FAMILY SUPPORT SERVICES WHICH WE PROVIDE, I HAVE BROUGHT ALONG SOME LITERATURE WHICH I WOULD BE HAPPY TO SHARE WITH YOU.

I WOULD LIKE TO EMPHASIZE THAT IN FIGHTING FOR THE PROVISION OF THESE SERVICES, WE MUST ADVOCATE FOR THE ESTABLISHMENT OF PROGRAMS WHICH OFFER FREEDOM OF CHOICE, PROGRAMS AND SERVICES WHICH ARE FLEXIBLE AND WHICH OFFER CLIENTS AND PARENTS ALIKE A VARIETY OF OPTIONS.

IN THIS PRESENTATION I HAVE SOUGHT TO SHARE WITH YOU MY DEEP CONVICTIONS REGARDING THE IMPORTANCE OF ADVOCACY, AND TO REMIND YOU THAT THE STRUGGLE TO ENSURE THE RIGHTS OF PEOPLE WITH HANDICAPS IS AN ONGOING ONE. WE MUST NEVER ALLOW OURSELVES TO BECOME COMPLACENT. INDEED, IF WE ARE TO REMAIN TRUE TO OUR PROFESSION, WE MUST INTENSIFY OUR EFFORTS TO SECURE DECENT AND HUMANE SERVICES FOR MENTALLY RETARDED CITIZENS; TO DEVELOP AND IMPLEMENT FAMILY SUPPORT SERVICES WHICH WOULD KEEP FAMILIES TOGETHER; AND TO ADVOCATE FOR LAWS AND REGULATIONS WHICH WOULD PREVENT THE DEGRADATION AND DEHUMANIZATION OF INNOCENT HUMAN BEINGS.

THOSE OF US WHO ARE ACTIVE IN THE SOCIAL SERVICE PROFESSION PLAY A VITAL ROLE. IN THE TRUEST SENSE, WE ARE FREEDOM FIGHTERS, CARRYING ON THE STRUGGLE FOR THE CIVIL AND HUMAN RIGHTS OF MENTALLY RETARDED AND DEVELOPMENTALLY DISABLED PEOPLE.

IN THE FACE OF FINANCIAL AUSTERITY OR ATTITUDINAL SHIFTS, WE CANNOT CHANGE OUR MOST STRONGLY HELD BELIEFS IN THE RIGHT OF ALL INDIVIDUALS, REGARDLESS OF THEIR DISABILITIES, TO HAVE THE OPPORTUNITY TO ACHIEVE THEIR FULLEST POTENTIAL.

AS LEADERS IN THE SOCIAL SERVICE FIELD, WE MUST SERVE AS ADVOCATES BEFORE LEGISLATORS AND OTHER GOVERNMENT DECISION-MAKERS.

INSTEAD OF LETTING THEM DWELL ON THE COST OF A COMMUNITY-BASED RESIDENCE OR PROGRAM, WE MUST EDUCATE THEM ABOUT THE COSTS--IN HUMAN AS WELL AS FINANCIAL TERMS--OF NOT PROVIDING SERVICES. WE MUST INFORM THEM THAT THE BOTTOM LINE IN HUMAN SERVICES IS NOT ONLY FISCAL, BUT ALSO MORAL.

WITH REGARD TO SHAPING PUBLIC ATTITUDES, WE MUST RECOGNIZE THAT FEAR AND MISCONCEPTIONS ARE AT THE ROOT OF MOST OPPOSITION TO COMMUNITY RESIDENCES AND OTHER COMMUNITY-BASED PROGRAMS, AND THAT THE ANSWER LIES IN PUBLIC EDUCATION AND INFORMATION, AS WELL AS IN WHERE AND HOW SERVICES ARE DELIVERED.

THOSE OF US WHO SERVE AS HEADS OF AGENCIES AND AS FELLOW PROFESSIONALS CARRY A HEAVY RESPONSIBILITY. IT IS WE WHO MUST SPEAK OUT AND SPREAD THE MESSAGE THAT THERE ARE PEOPLE WITH NEEDS AND RIGHTS OUT THERE, AND THAT A SOCIETY WHICH REGARDS ITSELF AS DECENT AND CIVILIZED MUST SEE TO IT THAT THESE NEEDS ARE FULFILLED AND THAT THESE RIGHTS ARE RESPECTED IN THE MOST NORMALIZED FASHION.

LET US ALL JOIN TOGETHER TO ENSURE THAT THE RIGHTS OF EVERY INDIVIDUAL, REGARDLESS OF HIS OR HER DISABILITY, ARE PROTECTED NOT ONLY TODAY, BUT FOREVER MORE. TOGETHER, WE CAN MAKE THIS HAPPEN. TOGETHER WE WILL MAKE IT HAPPEN. FIGHT ON!

THANK YOU.